Introducing a weak presumed consent for organ donation – is it ethically justified?

Fankhauser, Christian Daniel ; Benden, Christian

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Department of Urology, University Hospital Zurich, University of Zurich, Zurich, Switzerland

Division of Pulmonology, University Hospital Zurich, University of Zurich, Zurich, Switzerland. Electronic address: christian_benden@yahoo.de

Introduction

In the United States, an increasing gap between the supply of and demand for solid organ transplants led to a public health crisis with currently over 110,000 patients waiting for a lifesaving transplant (1). Many organs originate from cadaveric organ donation, and donors are required to consent while alive, a concept often referred to as *expressed* consent. However, only 5% of all potential donors have a documented expressed consent, and therefore, also family members of the deceased patient may consent for donation, a process which is described as weak expressed consent (2). This difficult decision puts pressure on families and only 30% have previously discussed organ donation with the deceased (3). As a consequence, up to 60% of families do not approve organ donation of their loved ones, most commonly because of uncertainty and to minimize family distress in such already emotionally difficult situations (4).

To increase organ donation rates and release family members from difficult decisions, many countries changed from expressed to presumed consent (5). Presumed consent means that every adult has the opportunity to refuse donation, but in absence of such a record, one presumes consent. A further modification is weak presumed consent,

which allows family members to overrule a presumed consent, if they believe that the deceased would object donation. This essay focuses on the ethical reasoning behind the introduction of weak presumed consent for organ transplantation. From two ethical perspectives, namely utilitarian and libertarian, the authors argue why introducing presumed consent is ethically justified.

Utilitarian perspective

In deciding what laws or policies to enact, utilitarianism favors that “a government should do whatever will maximize the happiness of the community as a whole” (6). From a societal perspective, long waiting lists for transplants have a detrimental impact on life expectancy and quality of life. Furthermore, because transplantation compared to standard of care is cost-effective, organ donation rates should clearly be increased (7). However, several concerns regarding presumed consent have been raised and are addressed as follows.

First, some question the effect of presumed consent legislation on donation rates. A systematic review including 13 studies comparing organ donation rates in countries with or without presumed consent or after changes in legislation showed increased donation rates in all countries (5). However, critics argue that other innovations in the health care system rather than the implementation of presumed consent led to this increase. Nevertheless, because randomized controlled trials are unfeasible to conduct under these circumstances, we have to rely on the highest available evidence, which uniformly points into the direction that presumed consent increases donation rates.

Second, the relationship of trust between clinicians caring for patients at the end of life and their families is a fundamental prerequisite in health care, which should not be put at risk by changing the way of consent. Critics argue that the decision of donation

taken out of the hands of family members appears morally degrading leading to distrust. However, the authors do not believe that such situations will occur because weak presumed consent implies that families can always oppose if they believe that the deceased person would not agree.

Lastly, opponents argue that unawareness of the consequences of not opting out and insufficient access to donation registries prevents residents from refusing donation. The authors agree that it is mandatory to ensure that the preference of each resident is registered, but in developed countries, this can appropriately be established in the same way as many governmental services. Additionally, the authors suggest that the preference of each individual should also be reassessed several times, e.g. while applying for or renewing legal documents (e.g. passport, driving license). In summary, covering the beliefs of all residents requires a transparent informative campaign, accessible systems to record consent and ideally, a repeated assessment of consent.

A Libertarian replica

Many opponents of presumed consent argue that libertarian principles as freedom of choice and individual judgment (6) contradict per se with presumed consent, which the authors hereby oppose. A libertarian stance does honor that individuals have interest until death but also thereafter and their expectation regarding organ donation should be respected. Critics of presumed consent argue that in absence of a consent the default answer regarding donation can only be denial. However, as 80-90% of residents would principally favor to donate their organs (8), a default denial would ignore expectations of the vast majority of residents. Therefore, weak presumed consent, considering family expectations is more likely to reflect the preferences of deceased residents.

Conclusion

In summary, the public debate around consent for organ donations is very important as these discussions shed light on the public health crisis of donor organ shortage. Given some valid concerns, it remains key that (1) a transparent informative campaign precedes any legislative changes, (2) recording of patients' objections is facilitated by all means and (3) consent is reassessed at multiple time-points. According to the experience of many countries, presumed consent will most likely increase donation rates, however, to an unclear extent. Supporting interventions e.g. identifying potential donors and training health care workers will remain a cornerstone of donor organ donation systems (3, 5).

References

1. United Network For Organ Sharing. Waiting list candidates by organ type. July 2019 (https://www.unos.org/data/transplant- trends/ waiting - list - candidates - by - organ - type/).
2. Repräsentative Bevölkerungsumfrage, Ergebnisse der DemoSCOPE Erhebung.
3. Seiler CA, Bischoff P, Nett PC, Candinas D. Abnehmende Organspendebereitschaft als nationales Problem: Im Engagement liegt der Lösungsansatz. Schweizerische Ärztezeitung. 2006;87:4.
4. Shaw D, Georgieva D, Haase B, Gardiner D, Lewis P, Jansen N, et al. Family Over Rules? An Ethical Analysis of Allowing Families to Overrule Donation Intentions. Transplantation. 2017;101(3):482-7.
5. Rithalia A, McDaid C, Suekarran S, Norman G, Myers L, Sowden A. A systematic review of presumed consent systems for deceased organ donation. Health technology assessment (Winchester, England). 2009;13(26):iii, ix-xi, 1-95.
6. Sandel MJ. Justice: What's the right thing to do?: Macmillan; 2010.
7. Haller M, Gutjahr G, Kramar R, Harnoncourt F, Oberbauer R. Cost-effectiveness analysis of renal replacement therapy in Austria. Nephrology Dialysis Transplantation. 2011;26(9):2988-95.
8. Webb G, Phillips N, Reddiford S, Neuberger J. Factors Affecting the Decision to Grant Consent for Organ Donation: A Survey of Adults in England. Transplantation. 2015;99(7):1396-402.